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Winter 2002

# The MSAA MOTIVATOR

Magazine for people with multiple sclerosis

## PAIN

### Unnecessary With or Without MS

NIH's Dr. Ann Berger serves tea and  
dons funny costumes to help people  
cope with pain and chronic illness.



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WITH OR WITHOUT  
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Pain is real.

"Pain is whatever the person feeling it says it is," says Dr. Ann M. Berger, RN, MSN, MD, and chief of pain and palliative care services at the Clinical Center at the National Institutes of Health (NIH) in Bethesda, Maryland.

"No matter where he or she says it is," Dr. Berger continues, adding with emphasis that considering current treatment options, pain also unnecessary.

Confirming the reality of pain may seem simplistic, especially to *Motivator* readers who cope with pain on a daily basis. Declaring its needlessness is downright controversial. But both statements must be made boldly because, historically, pain has been the stepchild of healthcare. Too frequently it is considered an effect of a larger physiological situation and is therefore denied, dismissed, disregarded, or untreated once its purpose as a presenting symptom – the sign that prompts one to visit a doctor or seek admittance to a hospital – has been served and the "causing" disease diagnosed.

Acknowledgement of pain and its treatment, especially when chronic, are heady issues in healthcare today, and any statement that says pain can and should always be relieved draws advocates from



*Dr. Ann M. Berger, RN, MSN, MD, and chief of pain and palliative care services at the Clinical Center at the National Institutes of Health (NIH) in Bethesda, Maryland*

several points of view into the fray.

Discussion of these issues is especially important to people with MS because for a long time they were commonly told that pain is not associated with MS and does not need to be considered in an overall treatment program. In the Summer 2001 issue of *The Motivator*, MSAA Medical Advisor, Dr. Jack Burks, debunked that, saying "over 50 percent of individuals with MS experience pain associated with their illness." People with chronic pain from MS will be particularly interested in what Dr. Berger and the American Pain Foundation have to say about speaking to at-

tending physicians about pain, insisting on treatment for pain, and the safe use of pain-relieving drugs that have sparked controversy of their own, i.e. oxycontin.

"Pain is a vital sign that should be assessed in every patient," Dr. Berger says. "It is often the wakeup call that alerts someone that something in their body needs attention. It may be an initial presentation symptom of MS.

"Problems ensue because of what happens to pain after a disease is diagnosed. At that point, there is a propensity to treat the disease but not to look at or treat the symptoms.

"Pain or any chronic symptom deserves



no less attention, care, or treatment than the disease as a whole. As an example, let's say someone with MS reports having chronic pain. Let's go further and say this pain is not controlled by the drug prescribed to control the disease, for instance one of the ABC drugs. It must be treated separately, in addition. But, many doctors, neurologists included, are terrified of pain. Treating it is not part of their protocol. They let the symptom go without treatment, and the patient suffers.

"I ask how prescribing something to deal with chronic pain is different from prescribing a substance to deal with any chronic vestige of a disease, even if it has to be taken for a person's entire life. In cases of diabetes, for instance, no one blanches at the prescription of a lifelong taking of insulin.

"One diagnosed with MS can have total body pain, but it's the lesions that will be missed even if it might be the pain that is more debilitating. Symptoms can go on for years without receiving significant treatment attention. Think about it. A patient comes in and receives a \$1 million workup that buys a proper and accurate diagnosis, yet the patient still walks out with symptoms. Relievable symptoms. Opioids are not prescribed, and because of current publicity, fear of them, among doctors is rife.

"This scenario becomes worse when the person is told pain does not derive from the disease. Imagine how frustrating and possibly depressing it must be for one to hear the pain he or she so palpably feels is 'not real.' I say if a person reports pain, then that person should be believed and the pain should be dealt with.

"Pain is not just a physical matter. Total pain is the sum of physical pain plus suffering composed of psychosocial and spiritual dimensions. It can keep people from sleeping, make them feel more isolated,

afraid, or reclusive, and preclude any semblance of a normal life. One should not have to live with it. All suffering is unnecessary, and therefore should be treated."

Dr. Berger says the answer to more attentive treatment for people with chronic pain and other relievable symptoms can be found in the evolving discipline of palliative care, another of her specialties.

"Palliative care is an offshoot of the hospice movement," Dr. Berger says. "When people hear it, they think we are talking about end-of-life or terminal situations. But people with chronic illness and chronic symptoms need the same diligent and compassionate attention as people in the last stages of terminal diseases.

"Someone with MS, who can live with the disease for 30, 40, 50 years, may need it more. Especially because at different stages of the disease, a person with MS has different matters to deal with.

"Palliative care gives ease to the person in all stages and vestiges of an illness. It involves a system of integrative care, a team approach composed of professionals in many different specialties such as medicine, nursing, social work, spiritual ministry, recreation therapy, music, art, massage, acupuncture, and rehabilitative medicine.

"One problem in medicine today is doctors cannot afford to spend unlimited time with their patients. That's why they tend to concentrate on disease instead of symptoms. That's why they want to deal with the immediate, prescribe medication, and move on to the next patient. It's faster, more efficient. To maintain an office, hire nurses and other staff, replace equipment, and make a living, a doctor knows how much his or her office has to earn each hour. Often, that determines how much time he or she will spend with one patient.



"There is no reason why a person has to rely on one doctor or why a team of doctors and professionals treating one person for various aspects of a disease cannot consult about that patient at reasonable intervals. We just have to put such a system into practice. Ideally, medical facilities would be established on this type of model. Until then, individual patients should consider building a team of integrated specialists and managing the communication among them.

"A team approach is especially important when it comes to pain. A person with MS may rely on his or her neurologist for everything concerning the disease. But that person could go to a pain management specialist who will deal with that symptom and work with the neurologist to make sure the work each is doing is complementary.

"Remember the equation of physical pain plus suffering. A team dealing with a disease may not be composed only of doctors. Pain needs to be treated in terms of physical symptoms, spiritual symptoms, psychological symptoms, and quality-of-life issues (lack of energy, worrying, feeling sad, feeling nervous, having difficulty sleeping). Suffering is not always helped by medicine alone. Pets, music, massage, etc. are sometimes needed to augment or be part of a program of total care. Meditation could be as helpful or as integral as medication."

Since establishing the department of pain and palliative care at NIH in August 2000, Dr. Berger has put her theories into practice. The shelves of her office are lined with funny hats, stuffed animals, and feather boas that she dons and takes on her rounds for patients at NIH to wear. These items give people a chuckle and make life a little lighter for them. In Dr. Berger's office is also a teacart that features cups, saucers, and other setting

pieces in a pattern reminiscent of Royal Crown Derby. It's used to create tea parties for NIH patients.

"Chronically ill people are usually treated with a steady diet of seriousness. It's important to add some levity to their lives. It's also important to touch. Chronically ill people do not get touched enough.

"The pets and tea parties augment the medical treatment. Attention to the spiritual and psychosocial dimensions has to accompany attention to the physical. It's all part of the team approach I think would be of benefit to any person with any type of chronic life-long, life-threatening illness."

Because patients' reports of chronic pain have been dismissed so often, Dr. Berger says pain does not always enter the conversation between doctor and patient.

"A lot of people don't even ask about pain even though it is a symptom they

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have repeatedly. I believe people should talk about anything that is troubling them.

"A person may have to stand up, say they've had enough, and insist on treatment. They may even have to change their physician. If enough people do this, the medical community would be forced to listen.

"Patients should be encouraged to ask questions about pain.

Doctors can be pressured, even if they're not pleased, to answer. With a team approach, the primary care physician, or in the case of someone with MS, the neurologist, can refer a patient to a pain management specialist. That specialist should

only consult with the patient but with his or her family. Doctors are not alone in dealing cavalierly with pain. A person's family can also think they're being kind by trying to minimize the severity of a person's situation and say things like 'it's not that bad' or 'you can handle it.' Some in a

family may not believe it when a patient says he or she is in pain. The important thing, when no one is listening to what a person says he or she feels, is to make an appointment with a pain management specialist who will take the matter seriously. This helps psychologically as well as physically. One no longer believes all the people who said he or she was exaggerating or 'nuts.' One will believe the people

who say pain is not necessary. And all will be impressed when the person demonstrates all he or she can do once relieved of pain."

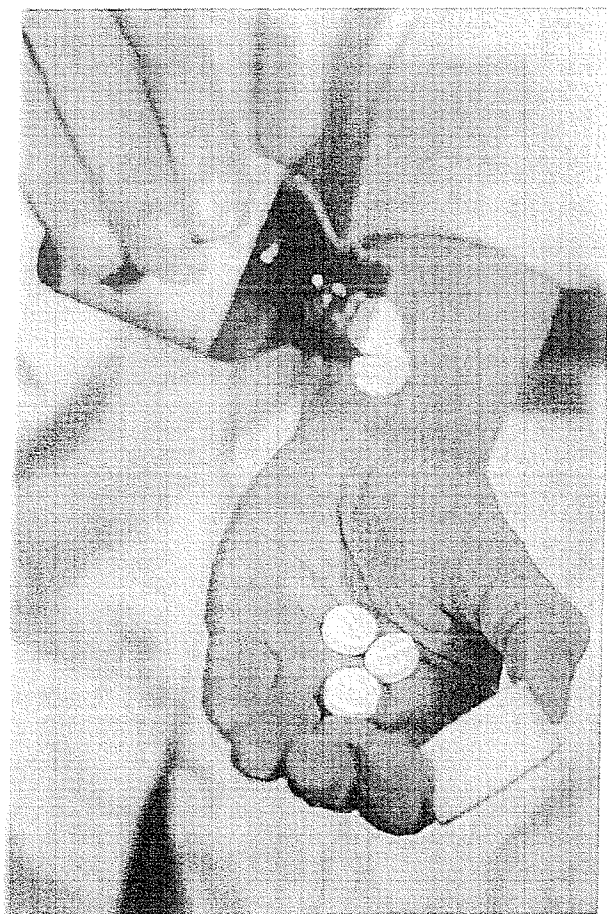
A patient can help a doctor or member of his or her treatment team if he or she can be accurate in describing the pain he or she is feeling.

"Pain is individual," Dr. Berger says.

"It's different for each person. That means modalities will be different for all people and that on an individual basis, we need to address the spiritual, psychological, and psychosocial in addition to the physical side of each patient."

Charts in a presentation Dr. Berger uses when lecturing are useful in helping a person define his or her pain with some precision. People should be careful to note the site of the pain, its severity, the date of its onset, its duration, any aggravating or relieving factors, and its effect

on physical and social function. To judge the quality of pain, one should determine if it is sharp, stabbing, dull, cramplike, aching, throbbing, shooting, burning, numbing, pulling, radiating, tight, or responsive to pressure. One should also pay attention to factors that exacerbate or calm the pain. These could be movement, bending, sitting, lying flat, standing, walking, eating, or swallowing as well as changes in the weather, a specific time of day, or distractions.





The more information a person can give a member of one's treatment team about the nature of his or her pain, the better that professional will be able to prescribe the right relief. The American Pain Foundation recommends keeping a *Pain Diary*. In it, the person chronicles where a pain is, how it feels, if he or she had it when he or she woke up, if it changed during the day, if anything makes it feel better or worse, if any medicines help or make matters worse, if any medicines were stopped because of their side effects, if anything besides medicine helps the pain subside, if sleep is disturbed or made impossible by the pain, if the pain precludes spending time with family and friends, if it makes one skip meals, and if it has changed the person's life.

Several ways to control pain are known. To ease her own pain following surgery for breast cancer, Dr. Berger relied on acupuncture. The most common method of dealing with pain, however, is through pharmaceutical means, and the stronger the drug, the most controversial the treatment.

In some cases, the issue revolves around public perception of a particular drug. In others, people need reassurance concerning the difference between dangerous addiction and harmless physical dependence.

"The purpose of pain relief is to remove suffering," Dr. Berger says. "Most physicians want to help a patient. Unfortunately, many do not have a clue about what to do for pain. We have a variety of remedies and procedures available to us to treat chronic pain. There are nonsteroidals, opioids, and adjuvants such as antidepressants and anticonvulsants. In severe cases there are blocks or invasive procedures.

"Much of the time, we will use drugs. These can be mild, moderate, or severe, depending on the pain. They also put fear into many prescribing physicians.

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"The media is responsible for this. They seize on drug stories. They find cases where an opioid is being abused or sold illegitimately, and they brand it as being bad, harmful, or dangerous. They never say if an opioid is used responsibly under the supervision of a knowledgeable physician or palliative care team, it is an effective and useful means of relieving pain.

"Doctors in general are afraid to treat pain with opioids. Some are afraid that every time they write a prescription, the DEA or the state (licensing) boards will be looking over their shoulder and, perhaps, pull their license. As physicians, we have to get over that. Like fire, opioids can be friend or foe. It depends on how they're administered. An able doctor can make sure they remain a friend.

"A responsible physician can explain to a person the difference between addiction and physical dependence and make a convincing case for a drug that can be controlled and help the patient.

"Addiction implies improper, illegal, and non-medical use of a substance. The addict loses control over their use, which becomes compulsive and harmful. They continue to take a drug in spite of the harm. They are not patients. They seek the drug for the sensation it gives them.

"That cannot be compared to taking a legitimate treatment, opioid or otherwise, under the control and administration of a physician. Taking codeine or morphine to

relieve pain as part of a therapeutic regimen is no different from taking insulin to control diabetes.

"The use is managed. A specific dose is prescribed for a specific time. It can be increased or decreased according to need. It can be adapted to balance side effects. Science and logic are at work here. All is being monitored. The drug is not being used for reckless recreation.

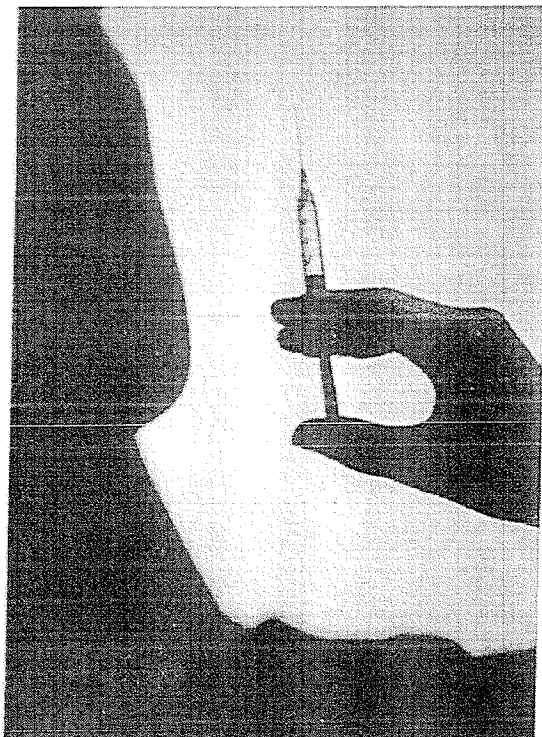
"Physical dependence is misunderstood. There is nothing bad about it unless the

managing substance, opioid or otherwise, is abruptly removed from the patient which would precipitate a withdrawal symptom. This is a circumstance no practitioner would willingly allow. This can be avoided by tapering medications slowly before discontinuing them. Other than that, physical dependence is a safe, regulated byproduct of relief. You can either take the substance that causes relief or be in pain and miserable. The choice is up to the patient.

"In the case of MS, if an opioid or other medication is useful to con-

trol a symptom and restore equilibrium and a desire to participate in life, I'd advise my patient not to worry about physical dependence. Cessation of pain is worth it.

"Nobody has to live with pain. That's the important message I want to impart. It's one I think should have advocates all over the country. Physical dependence is minor compared to a lifetime of pain and the problems it can cause."



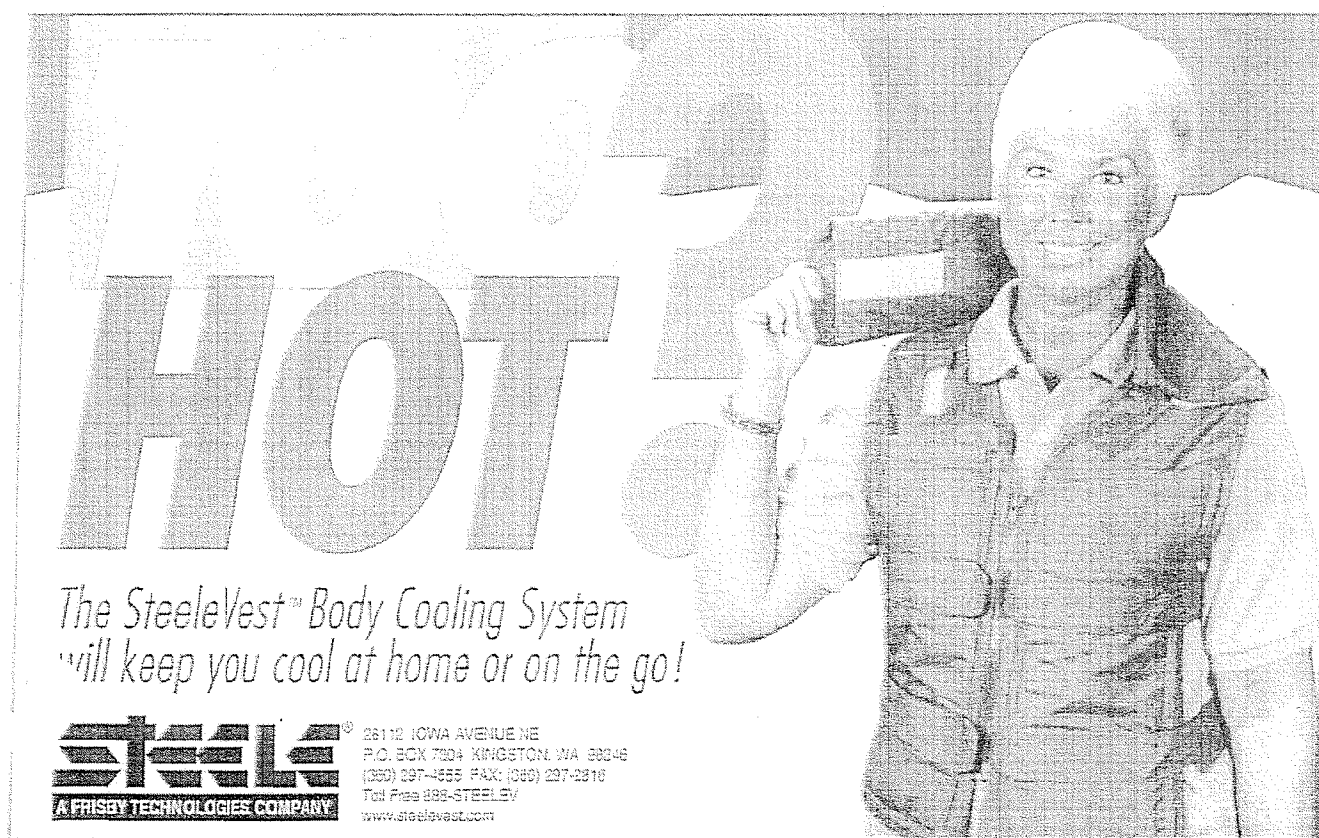
Dr. Berger began her career as a registered nurse and went on to attain her master's degree in nursing from the University of Pennsylvania. Much of her early career was spent as an oncology nurse specialist. It was while working with people with cancer that she developed her interest in palliative care and supported a team approach to medical treatment. She returned to school to earn her M.D. degree from the Medical College of Ohio in Toledo. From there, she did her residency at Hartford Hospital in Connecticut and completed a fellowship in medical oncology, pain, and palliative care at Yale University, where she initiated a palliative care service. From 1996 to 2000, Dr. Berger was on the faculty of the University of Medicine and Dentistry of New Jersey in Camden, where she advanced her work in palliative care at Cooper Hospital. In August 2000, when NIH decided to add a pain and palliative care department, Dr. Berger

was tapped as its inaugural chief.

"My interest has always been in pain and palliative care so I could concentrate on symptom treatment and relief of suffering," Dr. Berger says. "I came to NIH because it makes a commitment to making palliative care and a team approach part of the medical protocol of its hospital. I listen to patients and tell them I understand – I know – why they want and require care. Then, I set about giving them that care in a way that integrates with everything else that is happening at NIH. I hope someday such a team approach is available everywhere and that a team approach, especially in the area of pain management and palliative care, becomes a routine part of treatment for people with MS."

— Neal Zoren

*See the Pain Resources List  
on Page 24*



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## PAIN RESOURCES

American Academy of  
Pain Management  
13947 Mono Way, Suite A  
Sonora, CA 95370  
Phone: (209) 533-9744  
E-Mail: aapm@aapainmanage.org  
Web site: www.aapainmanage.org

American Chronic Pain Association  
P.O. Box 850  
Rocklin, CA 95677-0850  
Phone: (916) 632-0922  
Email: ACPA@pacbell.net  
Web site: www.theacpa.org

America Pain Foundation  
111 South Calvert Street, Suite 2700  
Baltimore, MD 21202  
Phone: 888-615-PAIN (7246)  
Email: bweissfeld@painfoundation.org  
Web site: www.painfoundation.org

American Pain Society  
4700 W. Lake Avenue  
Glenview, IL 60025  
Phone: (847) 375-4715  
Email: info@ampainsoc.org  
Web site: www.ampainsoc.org

## PAIN CARE BILL OF RIGHTS

### As a Person with Pain, You Have:

The right to have your report of pain taken seriously and to be treated with dignity and respect by doctors, nurses, pharmacists and other healthcare professionals.

The right to have your pain thoroughly assessed and promptly treated.

The right to be informed by your doctor about what may be causing your pain, possible treatments, and the benefits, risks and costs of each.

The right to participate actively in decisions about how to manage your pain.

The right to have your pain reassessed regularly and your treatment adjusted if your pain has not been eased.

The right to be referred to a pain specialist if your pain persists.

The right to get clear and prompt answers to your questions, take time to make decisions, and refuse a particular type of treatment if you choose.

*Although not always required by law, these are the rights you should expect, and if necessary demand, for your pain care.*

The Pain Care Bill of Rights was reprinted with permission from the American Pain Foundation.



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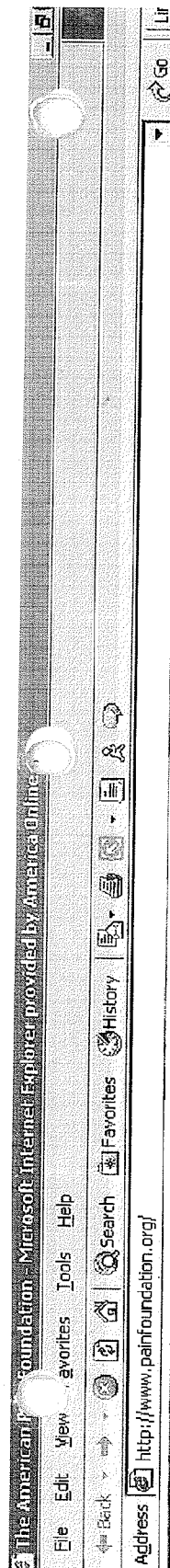
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### APF Web Site Has A New Look!

Third generation website is premier resource for people with pain and their families, the media, legislators and the general public. We have reorganized the site and are in the process of adding new information. Please let us know what you think and share your ideas with us by completing our Visitor Survey.

### New Guideline For the Treatment of Arthritis Pain

The American Pain Society (APS), a professional organization devoted to pain management, has released its new clinical guideline for treating acute and chronic pain associated with arthritis, a chronic disease that afflicts one in six Americans. The new APS guideline strongly emphasizes that arthritis pain is best treated through a combination of ongoing pain assessment, medication, proper nutrition, exercise and patient and family education. Read more about the new arthritis guidelines.

### American Geriatrics Society Releases Pain Guidelines

The American Geriatrics Society (AGS) released new clinical practice guidelines titled *The Management of Persistent Pain in Older Persons*. The guidelines include recommendations for pain assessment in cognitively impaired persons, the use of new COX-2 selective nonsteroidal anti-inflammatory medications, the unethical use of placebos, and many other contemporary issues in persistent pain management. Read more about the new geriatric pain guidelines.

### Special Features

[Pain Chats & Discussion Boards](#)  
(coming soon)

[Pain & End Of Life Care](#)  
(coming soon)

[Finding A Doctor](#)

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Rolling Pain Fact:  
Over 50 million Americans suffer from chronic pain, and nearly 25 million Americans experience acute pain each year due to injuries or surgery.

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# PainAid

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## Welcome To Pain Aid

We have, as promised, finally succeeded in launching this very special area with the help and guidance of the staff of the American Pain Foundation (APF). Perhaps some of you were active in America Online's Pain Relief Center forum (PRC). If so, you will see a number of familiar names that have volunteered their time to help manage PAIN AID.

### Why PAIN AID?

With the closing of the PRC last September, we found that there were few options available on the Internet that offer similar message boards and scheduled chats, yet lack the ambiance that made the PRC so special. While many web health-related sites may offer some content and perhaps even a single message board devoted to chronic and terminal pain, most appear as an afterthought. Even worse are the many ad banners and commercial endorsements. It is our policy to refrain from promoting any product, service, or goods; hence you will see no advertising. Any attempt to sell a product, service, or goods will not be tolerated.

### PAIN AID Mission

Our mission is to provide both discussion boards and conference (or chat) rooms for the purpose of educating both those who live with chronic/terminal pain and for those seeking information, first-hand accounts of what all who live with chronic pain must endure. Your peers provide support, information, and advocacy. In addition, we have a growing group of healthcare professionals who have volunteered their time to respond to

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September 27, 2003

Will Rowe  
Executive Director  
American Pain Foundation  
201 N. Charles St., Suite 710 Baltimore, MD 21201

Dear Will,

I know that you will be convening A Corporate Roundtable to consider the projects of the American Pain Foundation in mid-October. I would like to tell them how important that one of APF's projects, the National Pain Survey, is to the community of those concerned about pain, including patients, those who care for them, and to those doing research to try to find ways to reduce the national pain burden. Without such a benchmark study, national trends of pain improving or worsening cannot be demonstrated.

Because there has never been a population-based survey of pain in the United States, governmental, industry, and patient advocacy groups have no definitive data upon which to base their research, treatment, and policy-making efforts. Such a survey would establish the number of Americans experiencing pain, the various causes of pain, the severity of pain, and the effectiveness of current treatment. Without knowledge of the true magnitude of pain and its consequences, federal agencies cannot establish effective national policies on pain, pain research, pain treatment, and funding. Patient pain advocacy groups cannot successfully champion the very people they exist to serve. The pharmaceutical industry cannot easily find the incentive to develop new pain drugs and other treatments or devise clear-cut strategies to market its products.

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The American Pain Foundation has long realized that a definitive population-based pain study is greatly needed. Over the past two years, the APF has assembled an internationally recognized Scientific Advisory Board to design such a study. The advisory board includes experts in epidemiology, the physical basis of pain, the impact of pain on working and psychological health, and sampling and survey methods. This 2-year effort has been supported by startup funds from several pharmaceutical companies, and representatives of pharmaceutical companies have been involved in the development of the study's objectives.

The resulting National Pain Survey will at last define who is experiencing pain, the probable causes of pain, how much pain affects U.S. citizens, and the steps needed to lessen pain's impact. Briefly, the National Pain Survey comprises the following:

- A cross-sectional telephone survey of a nationally-representative sample
  1. Respondents must be U.S. residents at least 18 years old, and non-institutionalized
  2. Respondents may or may not have pain
  3. The sample size of 10,000 persons is powered to provide information on the prevalence of less-frequent types of pain, such as neuropathic pain
- Use of a random-digit dialing method to assure random selection of U.S. households and to assure state-level data
- A 20-to-30-minute interview on the following subjects:
  1. Pain by anatomical site – its severity and duration, and pain descriptors that will help us postulate the likely physical basis of pain (neuropathic, nociceptive, or mixed)
  2. Any associated medical diagnosis (diabetes, herpes zoster, cancer, arthritis, fibromyalgia, etc.)
  3. Pain interference – its negative impact on physical function, mental health, work, and productivity
  4. Pain treatment and satisfaction with treatment
  5. Perceived barriers to pain treatment
  6. Healthcare utilization associated with pain conditions
  7. Comorbidities that might impact function
  8. Psychosocial aspects of pain
- Extensive cognitive testing and pre-testing of questionnaires to assure data quality, and a Spanish version of the survey, to assure appropriate representation of Hispanics

I think the Foundation can be very proud of the work done by the National Pain Survey's Scientific Advisory Board in the development of the questionnaire. The resultant study will be expensive, but the value to those who will be helped by it

is enormous. I now that the Scientific Advisory Board is committed to the wide dissemination of these data in the very best journals. The challenge now is to make it happen.

Sincerely,



Charles S. Cleeland  
Chair, Department of Symptom Research  
U. T. M.D. Anderson Cancer Center, Houston  
Chair, National Pain Survey, American Pain Foundation

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Roundtable  
Attendees

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**APF CORPORATE ROUNDTABLE**

**October 20, 2003**

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